

# **Compilation of Social Studies**

*Universitas Indonesia iGEM Team 2016*

## **SOCIO-CULTURE PERSPECTIVE AND PSYCHOLOGICAL CONDITIONS IN VIEWING HIV/AIDS AND PEOPLE LIVING WITH HIV/AIDS IN INDONESIA**

The development of science and health technology does not simply guarantee that all health problems can be solved. HIV/AIDS is the example on how our science and health technology advancement has not yet solved this problem by finding its cure to eliminate the virus. In the global context, the distribution of HIV/AIDS continues to grow more rapidly. According to the World Health Organization (WHO), HIV test has not been distributed widely to several countries, thus if there is any HIV-positive person detected in the community, there is a higher possibility that there are several people in the community who already infected with HIV previously but unfortunately not detected because of lack of HIV test distribution or being promoted by its government. In the domestic context, the number of people living with HIV/AIDS (PLWHA) is similar to an iceberg phenomenon because the number of PLWHA stored in national database does not match the actual number.

According to database from Ministry of Health of the Republic of Indonesia in 2015, since 2005 until September 2015, there were 184.929 cases of HIV obtained from the reports taken from HIV counseling and HIV testing service. Additionally, the development of HIV/AIDS in several provinces in Indonesia continues to increase by number. DKI Jakarta ranked first in term of HIV/AIDS cases by 38.464 cases, followed by East Java 24.104 cases, Papua 20.147 cases, West Java 17.075 cases, and Central Java 12.267 cases. The problem that comes within this number of cases, there is no guarantee to ensure this information to be the exact numbers. Thus, the number of HIV/AIDS cases in Indonesia is feared to continuously grow becoming new kind of epidemic disease.

Having a diverse society in term of culture and beliefs, Indonesia raises its own issues in several domains for the people living with HIV/AIDS (PLWHA). There are number of domains that can be used as an analytical tool to asses the HIV/AIDS-related issues in Indonesia. Some of these domains, which highly influencing, are under the category of socio-cultural and psychological condition.

### **The Socio-Culture Perspective of Indonesia Society against HIV/AIDS**

Eastern values are deeply embedded and associated in the lives of the Indonesian people. Additionally, certain norms such as cultural, religious, and social norms are also embedded and correlating one to another. Values such as being abstinent before marriage, being loyal and committed to the marriage partner, having fulfilled certain roles that are accepted by society standards i.e. a wife should be focus to raise the children and manage the household, while husband should be focus to fulfill the household's needs in term of financial, are several example of what we may find in Indonesian society. Thus, deviant behaviors that lead to sexual-related issues such as pre-marital intercourse and same-sex relationship is commonly seen as source of problems within society because it is strongly against the values and norms in society. Diseases that might appear from these deviant behaviors are still seen as a 'fair punishment' for those having done these behaviors.

Conflict of values between multicultural societies—especially Indonesian societies—when looking at people with HIV are also sometimes accompanied by a belief or religion professed by Indonesia people. Like in Papua Province, as the province with the highest number of people living with HIV / AIDS in Indonesia, the culture and theology problem are closely linked with the development of HIV / AIDS. From a cultural perspective, Papua societies are very closed on the sex issue. Then there are some men who have more than one wife. Due to the closure of the HIV / AIDS reality, many people tend to close themselves and ignore the disease. According to Prof. Emmy Sahertian, instigators of HIV / AIDS in Indonesia, Wamena (one of the areas in Papua) there are some women who were burned for allegedly suffering from AIDS. Appears assumption in society that women who suffer from HIV / AIDS is a disgrace and should be burned, while men who died of HIV / AIDS they were buried with honor.

The discriminative understanding is not only presented in culture but there is also the theological construction on the issue of AIDS. AIDS is regarded as a disease curse of God and a person is required in a discriminatory manner. In some places, the church peoples have not considered and accept people living with HIV / AIDS as a brother or congregation. Based on the exposure, discriminatory conditions and stigma against people living with HIV / AIDS in Papua can give an idea of the actual socio-cultural perspective of the people of Indonesia toward HIV / AIDS.

### **Negative Stigma Affecting Psychological Condition People with HIV / AIDS in Indonesia**

Negative behavior of the local community towards people with HIV / AIDS can cause psychological trauma. Discriminatory act, neglect and violence to people with HIV / AIDS that sometimes occurs in Indonesia, can cause the patient feel alienated socially. Psychological aspects also include all parties or significant relationships that could affect the system and social functioning of people with HIV. Social relations that exist around HIV / AIDS could help sufferers of excessive psychological pressure, but the negative stigma and discrimination impede these patients receive social support. It is also encouraging the inability of people with HIV / AIDS in Indonesia do not have a strategy for managing stress that they faces. Event though, stress management is a form of self-defense mechanism that is essential for whole life and psychological condition of people living with HIV / AIDS.

The lack of social support from the society, not in tune with the concept of people in environment/ecological perspective which means that humans are part of the environment, HIV/AIDS disease will affect the person's malfunction and social system where he or she is (related to the system of family, community, and so on). When people living with HIV / AIDS are experiencing stress or depression, then the balance of the surrounding social system will also be hampered. This is because people with HIV / AIDS would have a specific role in the social circle. To overcome this, the social and health services and regulations established by the government should be able to optimize the potential of people with HIV / AIDS so that they can be empowered. Also, it is very important to provide education about HIV/AIDS issues and to make sure that the education is well-delivered to specific target of group or society especially group which highly affected by the HIV/AIDS issues.

### **Special Talk 1: Afternoon Talk with HIV/AIDS Counselor**

**Interviewee** : Mrs. Tika, Health Worker from RS Kramat, Jakarta

**Goals** : To gathering informations about status quo of HIV/AIDS treatment in Indonesia, engagement method for new HIV-positive person and problems within HIV/AIDS treatment in Indonesia.

**Output** : The findings and analysis about health dimension of people that living with HIV (problem and treatment in the health perspective)

There are discriminations toward people that living with HIV, including: (a) Discrimination in the work place, there are still practices that distinguish a worker with HIV and non-HIVo Education; (b). Discrimination shown by parents, forbid their children to play with students with HIV in schools. As the technology advances, the treatment of medical progress more visible and the health status of each person receiving treatment is also increasingly well, people with HIV began to dare open her health status and the means to add data of patients.

Based on these interview, we

### **Special Talk 2: Political-legal Perspective Of HIV/AIDS**

**Interviewee** : Mr. Haryo K. Utomo from UI Center of Study For Governments

**Goals** : To provide an overview about government or policy aspects of HIV in Indonesia, the government's role in addressing the problem of negative stigma to people living with HIV and a possible strategy for HIV treatment in the future.

**Output** : The analysis and findings that related to the Indonesian government's role and policy to address HIV problem

HIV is an iceberg phenomenon in Indonesia, it's mean that the official data regarding the case of HIV, does not correspond to the actual conditions about HIV disease in the field-number of the HIV cases are more due to low reporting the illness. There is a trend change on the most vulnerable groups affected by HIV disease—from LGBT into housewife group—and increased pre-marital sexual activity that triggers higher incidence of HIV in Indonesia. Therefore, then we tried to find out the information about the role and Indonesian government strategy to tackle HIV cases also government support for biological research development.

Based on the studies we have done, it is known that the governments are the most important role in the prevention of HIV cases in Indonesia. The government is trying to eliminate the negative stigma against people with HIV through advertisement and socialization, but government efforts are not paying attention about the innovation and digital culture condition of Indonesian society. Collaboration between government and non-governmental organizations that focus on HIV has not been established so that efforts are made to overcome the negative impact of HIV disease is still separated. In addition, tight budget is also an obstacle for the government to establish prevention and treatment strategies toward HIV disease effectively.

Furthermore, biological research to develop an appropriate treatment for HIV disease is still very minimal. Problems that related with lack of biological research in Indonesia is essentially constituted by funds limitedness, lack of knowledge and lack of experts in the field of biological research. These condition also underlies the slow development of synthetic biology-based industries in Indonesia. Then vaccines development as a major area of our project teams also got a great challenge in terms of acceptance from the public, biological research for development and innovation and lack of government support toward vaccine distribution evenly.

In the end, from these perspective, it can be concluded that in order to overcome the problems of HIV in Indonesia, we need a holistic and integrated roadmap. That is, when a roadmap has been established, the roadmap could be a strategic plan to address the HIV disease by improving the collaboration of various sectors—for example, non-government, international organizations and industry sector—and making the clear flow of funds, intervention strategy and objectives. With the establishment of the roadmap, then HIV cases in Indonesia can be monitored and reduced.

### **Special Talk 3: HIV/AIDS In The Eye Of Gay Community**

**Interviewees** : Mr. Cloud and Mr. Sent (*Inisial Name*)

**Goals** : To describing the real condition about high risk community toward HIV—gay as neglected community, in these context—and their response about HIV and the treatment possibility in the future.

**Outputs** : The finding and analysis about neglected community perspective toward HIV

Following is the interview result (testimony) from Mr. Cloud and Mr. Sent about their perspective toward assumption that LGBT is the most vulnerable group to HIV.

*“In my opinion, if someone asks me whether or not LGBT is the most vulnerable group to be exposed to HIV/AIDS, I would honestly say that it is indeed a fact. But, here in Indonesia, there are some groups that undertake the mass opinion so that everyone would believe that LGBT is the only group that are vulnerable to HIV/AIDS. But if we look closely, HIV does not spread only within the LGBT, but also within the hetero if they are doing unsafe sex with many partners, for instance.”* (Mr. Sent)

*“Yeah, so, in my opinion, if someone puts a stigma on us as LGBT, about higher tendency to get HIV compared to the hetero, yes I found it true. We are more likely to be exposed on such viruses. But hey! That only happens if we dont protect ourselves and if we do some risky behaviors. Even if you are a hetero but you routinely have sexual intercourse with different partner, you will also get the virus. So LGBT and hetero both are vulnerable to HIV. Therefore together we should stop the likelihood of getting HIV, moreover, like you said, better if we have a vaccine for it.”* (Mr. Cloud)

Based on the results of the interview above, it is known that they were aware if their group—LGBT—is the most vulnerable group to HIV than others; on the other hand, if they have a safe sexual behavior patterns—eg using condoms or the pill—then the risk of HIV disease can be avoided.